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Realities of Living in Maine with a Disability

Maine Developmental Disabilities Council

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Maine Developmental Disabilities Council

Realities of Living in Maine with a Disability

January 2011

This information is provided in accordance with the requirements of Title 34B, §17001(7), which requires the Maine Developmental Disabilities Council, pursuant to its duties under the federal Developmental Disabilities Assistance and Bill of Rights Act of 2000, to provide information from the comprehensive review and analysis of services, supports and other assistance for persons with disabilities required by 42 United States Code, Chapter 144, Section 15024(c)(3) to the Legislature by January 31st of each year.

Julia Bell
Executive Director
January 31, 2011

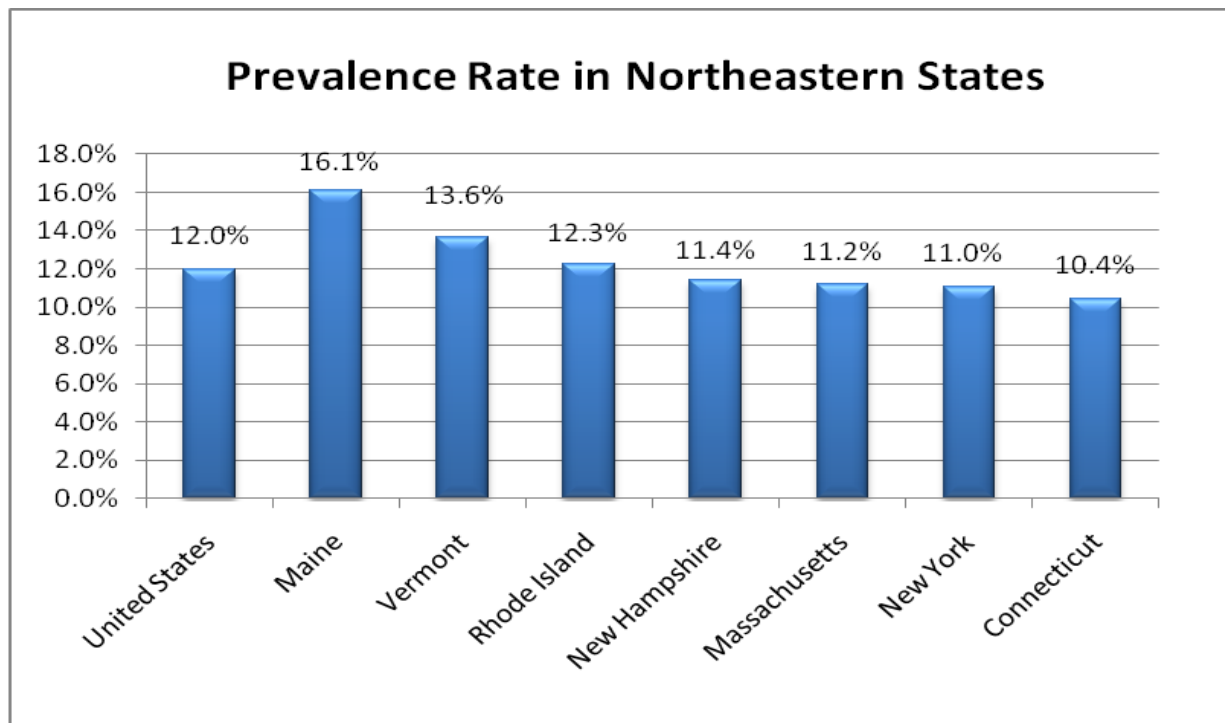
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PREVALENCE RATE OF DISABILITY - PEOPLE IN MAINE AGES 5 AND OLDER IN 2009¹

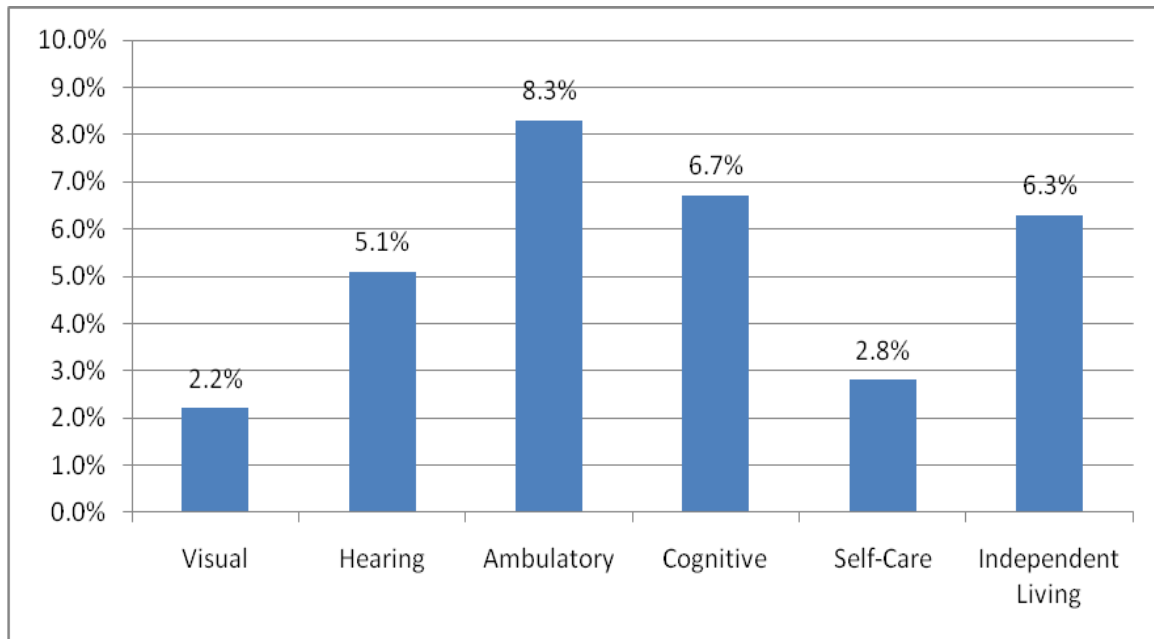
The prevalence rate of disability among people across the life span in **Maine is 16.1%**, according to the **2009 American Community Survey** completed by the U.S. Census Bureau. This places Maine in fifth place in the country for the prevalence rate of disability among the state's population. Maine has the highest prevalence rate of any state in the Northeast. (This is an increase from 15.7% from 2008, which placed Maine in seventh place.)

The federal data documents the higher prevalence of disabilities among people living in Maine than in other parts of the country. **The national prevalence rate of disability among people in the United States ages 5 and older is 12.1%.**



¹ Statistics from the 2009 American Community Survey 1-Year Estimates, U. S. Census Bureau

PREVALENCE BY DISABILITY CATEGORY IN MAINE, 2009



According to the **2009 American Community Survey** completed by the U.S. Census Bureau:

- **16.1% of Mainers report having a disability**
Approximately 210,000 Mainers (*of all ages*) report having one or more disabilities.
- **2.2% of Mainers have a Visual Disability**
Approximately 28,600 Mainers (*of all ages*) are blind or have serious difficulty seeing even when wearing glasses.
- **5.1% of Mainers have a Hearing Disability**
Approximately 66,600 Mainers (*of all ages*) are deaf or have serious difficulty hearing.
- **8.3% of Mainers have an Ambulatory Disability**
Approximately 102,000 Mainers (*ages 5 or older*) have serious difficulty walking or climbing stairs.
- **6.7% of Mainers have a Cognitive Disability**
Approximately 82,000 Mainers (*ages 5 or older*) have serious difficulty concentrating, remembering, or making decisions because of a physical, mental, or emotional condition.
- **2.8% of Mainers have a Self-Care Disability**
Approximately 35,000 Mainers (*ages 5 or older*) have difficulty dressing or bathing.
- **6.3% of Mainers have an Independent Living Disability**
Approximately 65,000 Mainers (*ages 18 or older*) have difficulty doing errands alone such as visiting a doctor's office or shopping because of a physical, mental, or emotional condition.

EMPLOYMENT and POVERTY STATUS OF PERSONS WITH DISABILITIES

According to U.S. Census Bureau statistics², the economic status of persons with disabilities in Maine is significantly worse than that of persons without disabilities:

- **EMPLOYMENT RATE = 24.8% in 2009 (compared to 69.3% percent of those who do not have a disability)**

The employment rate for persons with disabilities varied by disability type. The employment rate for people with self-help and/or independent living difficulties (which would include many persons with developmental disabilities) was only 16.6%.

- **PERCENTAGE WORKING FULLTIME = 20.3% of those employed (compared to 51.4% of working-age people without disabilities who were working fulltime/full-year)**

The percentages of persons with disabilities working fulltime/full-year varied by disability type. The percentage of persons with self-help and/or independent living difficulties working fulltime/full-year was only 7.1%.

- **MEDIAN INCOME FOR INDIVIDUALS WITH DISABILITIES = 36% LOWER THAN PERSONS WITHOUT DISABILITIES**

The median income of working-age people with disabilities was \$17,222 in 2009. (The median income of working-age people without disabilities during the same time period was \$26,652.)

- **POVERTY RATE = 27.5% of working-age persons with disabilities living at or below the federal poverty level (compared to 8.3% for people without disabilities).**

² U.S. Census Bureau, 2009 American Community Survey

FACTORS IMPACTING THE FUTURE OF PEOPLE WITH DISABILITIES IN MAINE

HIGH SCHOOL DROPOUT RATE THREE TIMES HIGHER THAN FOR THOSE WITHOUT DISABILITIES

As of 2009, 20.9% of adults with disabilities 25 – 64 years old in Maine had less than a high school degree compared to 6.6% of people without disabilities in this age group. Educational attainment for persons with disabilities varied by disability type, with higher percentages of individuals with significant functional disabilities having less than a high school degree. The percentage of people with disabilities who have completed a four-year college degree is only 12.3%, while 31% of adults in this age range without disabilities have completed four or more years of college.

AGING CAREGIVERS

The aging of Maine's population stands to pose serious challenges to meeting the support needs of persons with developmental disabilities. Families continue to be the primary providers of care. According to a national statistics, an estimated 76% of individuals with developmental disabilities live at home. In 25% of these households, the family caregiver was age 60 or older and the average age of the member with a disability was 38 years. Because adults with developmental disabilities are living longer, families have a longer period of caregiving responsibility.³ **In Maine it is estimated that more than 3,523 persons with developmental disabilities are living at home with caregivers over the age of 60.**⁴

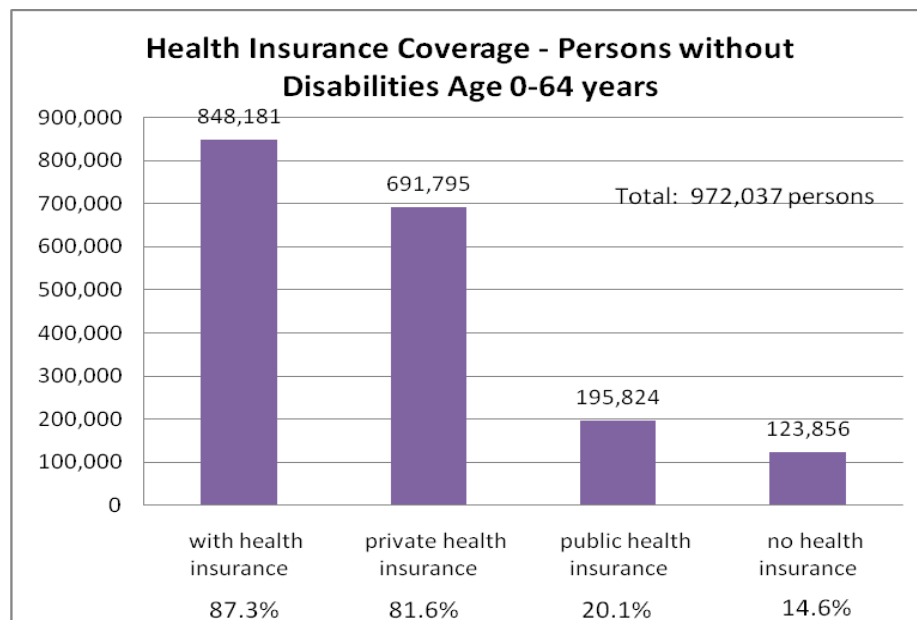
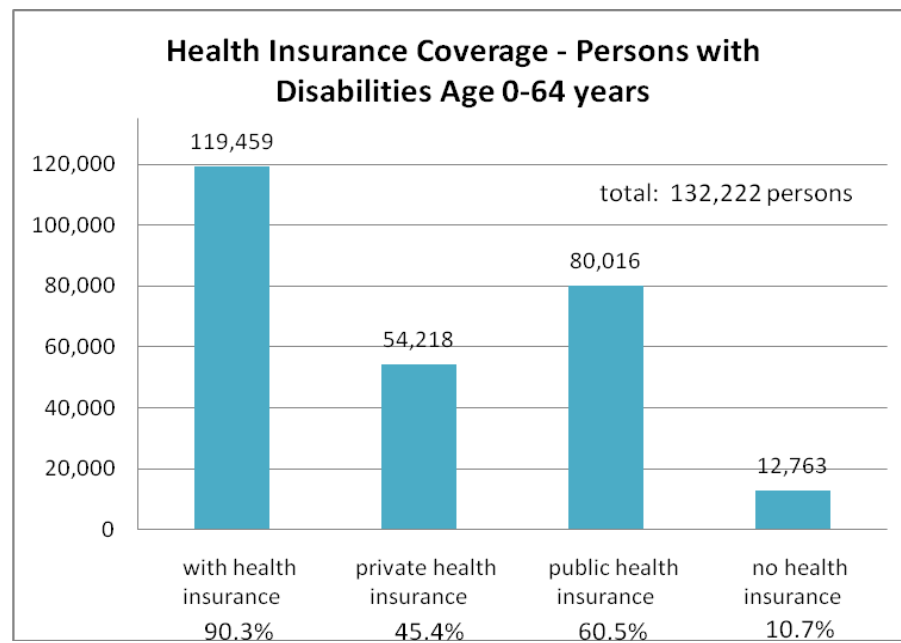
³ Tamar Heller, Ph.D., Rehabilitation Research and Training Center on Aging with Developmental Disabilities, Clearinghouse on Aging and Developmental Disabilities, Department of Disability and Human Development, University of Illinois at Chicago, 1640 W. Roosevelt Road, Chicago, IL 60608-6904

⁴ Braddock, et al. *The State of the States in Developmental Disabilities*. DD Council Review Draft February 6, 2011, The University of Colorado, Department of Psychiatry, School of Medicine.

HEALTH INSURANCE FOR PERSONS WITH DISABILITIES

Individuals with disabilities depend to a greater degree on publicly-funded health insurance coverage, given their numbers living in poverty and without employment. Individuals with significant functional limitations, which will include many with developmental disabilities, often depend on a variety of home and community-based services, in addition to primary and specialty medical care. These services support them in living with the greatest degree of independence possible, and enable many to be gainfully employed and otherwise contribute to their local communities. These services are financed through the State's MaineCare program.

The variance in financing of medical care for those with and without disabilities can be seen in the two charts below:



AVAILABILITY OF SERVICES

There is growing concern about the lack of available services for individuals with developmental disabilities as they exit the school system and the children's services programs administered by the Maine Department of Health and Human Services. Families talk about the looming "cliff" that their children face, with growing waiting lists for any of the adult services waiver programs available to individuals with developmental disabilities who qualify for Developmental Services.

Current Waiting Lists for Services as of December, 2010

The DD Council is required to report twice each year to the federal Administration on Developmental Disabilities in the U.S. Department of Health and Human Services on the status of waiting lists for services which utilize the federal funding sources named in the federal law (the Developmental Disabilities Bill of Rights and Assistance Act of 2000). Those federal funding sources include the Older Americans Act, Title V Maternal and Child Health, Title XIX (Medicaid), the Individuals with Disabilities Education Act, and the Rehabilitation Act. The charts on the next pages displays the most recent data collected from the pertinent state agencies and provided in the Council's annual report in December, 2010.

The items of greatest concern are:

- 1) **The dramatic increase in the waiting list for the Section 21 waiver program** – This is the Comprehensive Home and Community-Based Services Waiver that has been in existence in Maine for 26 years. As of October 2008 there was a waiting list of 69 individuals who had been found eligible for services, but were waiting for an opening in the waiver program. That waiting list has continued to grow, and as of January, 2011, there are 400 individuals on waiting for services. Of that number, 189 individuals are in critical need of services. This is a 580% increase from October 2008 – the list has grown almost 150% in the last ten months alone. The waiver continues to be closed to all but about eight new admissions each month, as vacancies occur, while at least that many are being added to the list at the same time. Of the total on the waiting list, 189 are in critical need of services; having been found to be at risk for their health and safety. In many cases this is due to the fact that their elderly parents are no longer able to care for them at home.
- 2) **The waiting list for the Community Supports waiver (Section 29)** – There are currently 1,404 individuals on this waiver program, which was started in January, 2008. When the waiver was closed in November, 2009, there was an immediate waiting list of 52 persons generated, and others are applying to be put on the waiting list. That waiting list has now grown to 228, with up to 100 expected to be added as the end of the school year approaches.

The potential need for services is reflected in the Department of Education's student count in four categories of special education as of December, 2008, as displayed in the chart below. These 2,875 students will be between the ages of 18 and 20 years as of June, 2011.

Some students with cognitive disabilities and/or autism spectrum disorders are served under the categories of "other health impaired" and "multiple disabilities." **If, however, only 50% of the students in the categories of "mental retardation" and "autism" are projected to meet eligibility requirements for Developmental Services (a very conservative estimate), that would be 283 individuals seeking waiver services.** (This does not include youth being served in special purpose schools or in out-of-state placements.)

STUDENT COUNT IN SPECIAL EDUCATION CATEGORIES

Age as of December, 2008	Multiple Disabilities	Mental Retardation	Autism*	Other Health Impaired
15 years	255	71	126	536
16 years	286	64	109	515
17 years	268	82	115	448
Totals	809	217	350	1,499

* The Autism category numbers are as of December, 2009. Data for the other categories was only provided as of 2008 by the State Department of Education.

WAITLISTS FOR STATE PROGRAMS SERVING PERSONS WITH DD

as of December, 2010⁵

Adult Services

Program	Waitlist as of December, 2009	Waitlist as of December, 2010	Percentage change	Comments
Home and Community Benefits for the Physically Disabled (Section 22)	108	103	Reduction of 4%	
Home and Community-Based Benefits for the Elderly and for Adults with Disabilities (Section 19)	0	0	Not applicable	Data specific to persons with DD not available
Home and Community Benefits for Members with Mental Retardation or Autistic Disorder (Section 21)	230	400	Increase of 333%	189 listed as Priority One, in “adult protective status”
Community Supports Benefits for Members with Mental Retardation and Autistic Disorder (Section 29)	52	228	No waitlist until November, 2009	This is the first waitlist since this waiver’s inception in January, 2008
Vocational Rehabilitation	1,063	0	Reduction of 25%	Federal Stimulus funds are being used to address the waitlist

⁵ Information provided by Maine Department of Health and Human Services and Maine Department of Labor

Special Education

Over the past ten years (from the 2000-01 school year to the 2010-2011 school year), there has been a 12 percent decrease in the number of students in special education programs in the public schools. However, there has been a dramatic increase in the number of students served in the Autism category during the same time period.

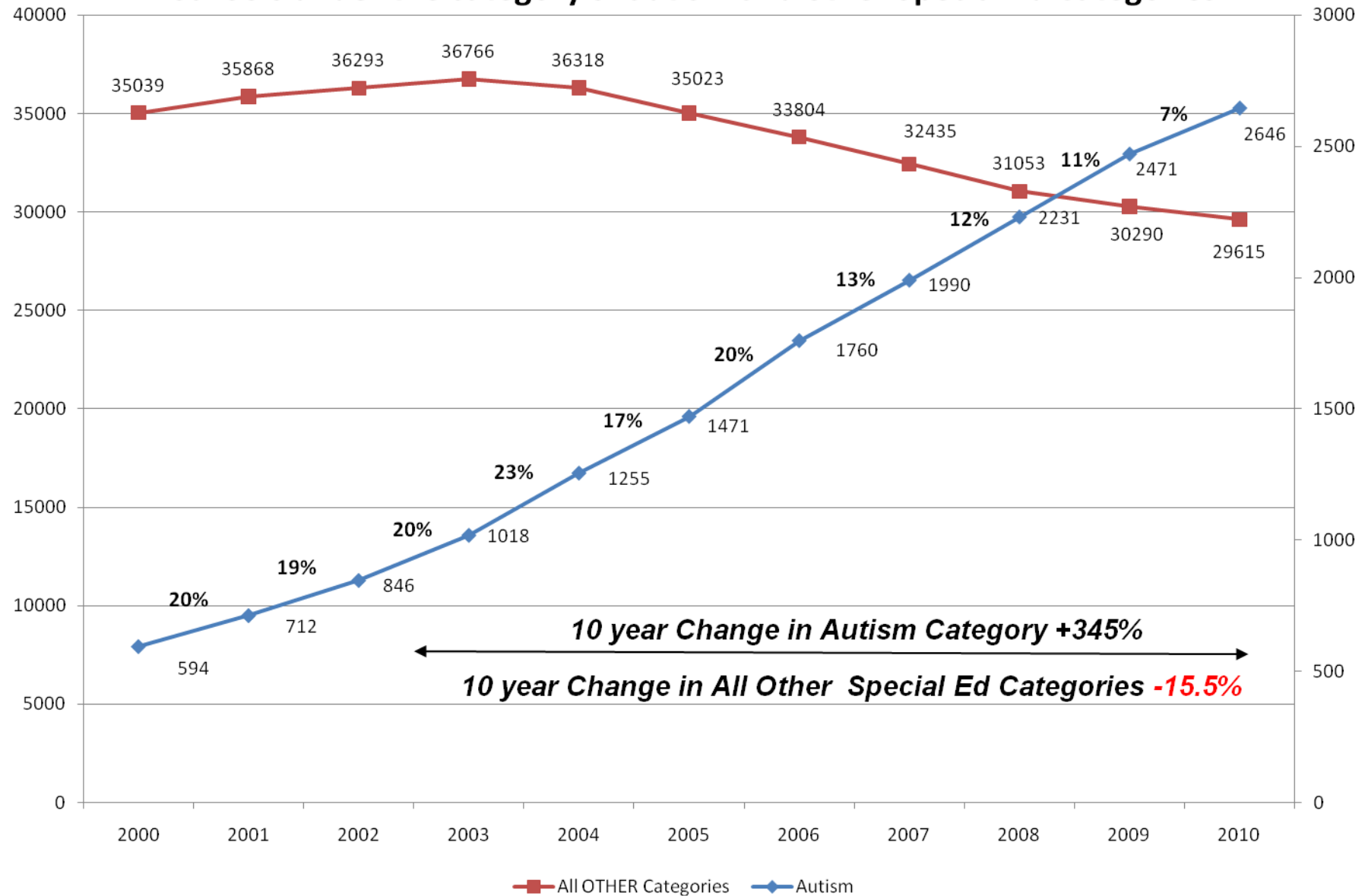
Concern has been raised regarding the cost of special education services having increased at the same time that the numbers of students receiving these services has decreased. This may be explained to a great extent by the relative change in numbers in various special education categories, given that students with some types of disabilities may require more supports and services as part of their educational programs.

The 12 percent decrease in the total special education population includes the following changes in individual categories over the same period of time:⁶

Category	2000-01 school year census	2010-2011 school year census	Percentage change
Autism	594	2,646	345% Increase
Emotional Disability	3,834	2,560	30% Decrease
Mental Retardation	1,063	722	29% Decrease
Multiple Disabilities	2,865	2,878	7% Decrease
Other Health Impaired	2,650	5,819	76% Increase
Specific Learning Disability	13,143	9,332	29% Decrease
Speech and Language	9,734	7,076	27% Decrease

⁶ Data provided by the Maine Department of Education, January, 2011

Comparison of 10-year trends in # of children served in Maine public schools under the category of autism and other Special Ed Categories



Data Source: Maine Department of Education, Office of Special Services Dec 1 Child Count

Prepared By: Maine Developmental Disabilities Council